Parent Guide

We are excited to share this content with you. If you are interested in finding more resources made especially for Parents, then check out these links to different areas of the **Twinkl Parents** hub.

SEND Support

Subject Guides

Pregnancy & Baby

Health & Wellbeing

Supporting Learning

@twinklparents

What is this resource and how do I use it?

This resource has been written to give support and advice to carers of children with Ehlers-Danlos Syndrome (EDS) and hypermobility. These are complex conditions affecting the connective tissues throughout the body and proper advice from a medical practitioner is required in addition to this guide.

What is the focus of this resource?

- Supporting Parents of Children with SEND
- EDS and Hypermobility Awareness
- Wellbeing

Further Ideas and Suggestions

You'll find lots more advice on our website for parents of children with different **SEND** conditions. Our **'Supporting a Child With...'** resources may be particularly helpful.

Parents Blog

Parenting Wiki

Parenting Podcast

Supporting a Child with Hypermobility Syndrome and EDS:

A Guide for Parents

What is Ehlers-Danlos Syndrome (EDS)?

EDS is a group of inherited conditions that affect connective tissues throughout the body. Connective tissues - like blood, bones or cartilages - have lots of jobs throughout the body. They bind tissues together, provide support, connect tissues to enable transporting of substances and help repair tissue damage.

There are several types of EDS, some having a greater impact than others, but all forms share symptoms such as increased joint movement or skin that stretches and can tear or bruise more easily.

What is Hypermobile Ehlers-Danlos Syndrome (hEDS)?

There are 13 types of EDS, of which hypermobility is the most common and often considered the least severe. It presents in most children as mobile joints, exercise-related joint pain, skin elasticity and sometimes with marfanoid elements (long limbs, tall). hEDS is caused by defects in collagen and family history also plays a part.

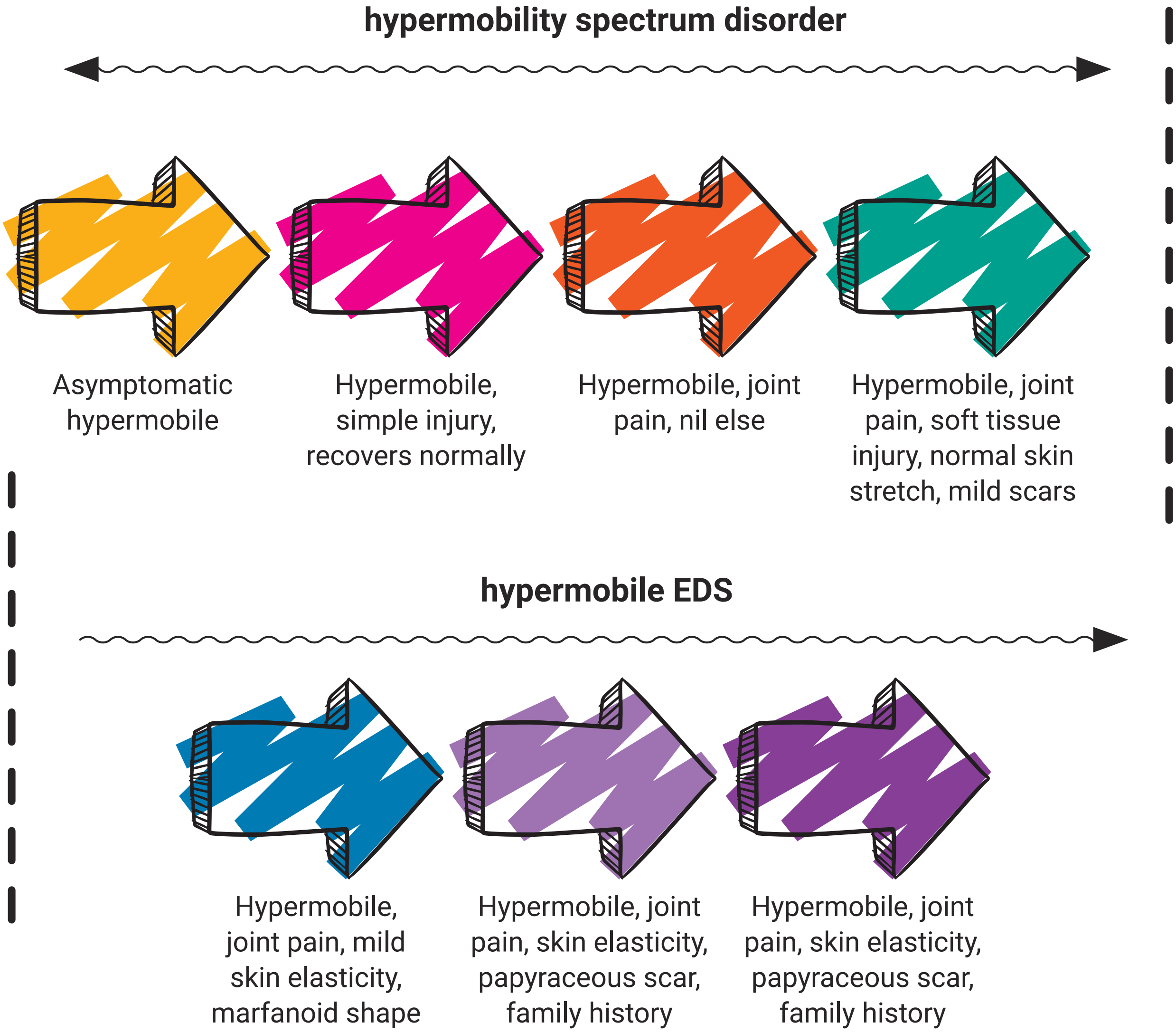
In many cases, children will outgrow hEDS, especially when they are supported by graded exercise and other physiotherapy. Those with more severe cases will continue to have symptoms into adulthood.

What is Hypermobility?

Children diagnosed with hypermobility have joints that can move further than average (more commonly called being 'double-jointed'). However, patients with HSD do not show all the features of hEDS or EDS. Depending on the severity of the condition, hypermobility can affect children negatively or not at all. Some children will suffer joint pain and extreme tiredness, while others will not. In fact, if there is no associated joint pain, being hyperflexible can help some children excel at sports.

What is the Hypermobility Spectrum Disorder (HSD)?

The term Hypermobility Spectrum Disorder has been adopted because every patient is different, has a different level of symptoms and will present in a variety of ways.



hypermobility spectrum disorder

Asymptomatic hypermobile

Hypermobile, simple injury, recovers normally

Hypermobile, joint pain, nil else

Hypermobile, joint pain, soft tissue injury, normal skin stretch, mild scars

hypermobile EDS

Hypermobile, joint pain, mild skin elasticity, marfanoid shape

Hypermobile, joint pain, skin elasticity, papyraceous scar, family history

Hypermobile, joint pain, skin elasticity, papyraceous scar, family history

Where a child places on the spectrum does not represent the severity of their symptoms, merely the range of symptoms.

Symptoms

Children found to be on the HDS will often have hyper-flexible or unstable joints that dislocate easily or click repeatedly when moved. They may also feel joint pain, extreme fatigue, indigestion and dizziness. Visual symptoms include skin that bruises easily, tears or lacks elasticity. Severe hEDS may also present as internal organ issues such as organ prolapse or valve problems, and may also cause problems with bladder control:

- Joint pain - a dull, throbbing sensation most commonly found in the legs, knees, feet and ankles, this pain comes on after activity or exercise. Back pain and headaches can also occur as a result of bad posture and weakened muscles.
- Fatigue - children may avoid exercise as a result of pain, making them feel more tired and have weakened muscles.
- Bruising - children with HSD can bruise more easily. This can be visually upsetting but usually causes no other concern.
- Clicky joints - cracking joints is a symptom of HSD and can encourage children to crack them deliberately, which may lead to dislocation.
- Tummy pain and constipation - reduced abdominal muscles can cause this.
- Fainting or feeling dizzy - this can be caused by slow blood pressure reflexes.

What next?

HSD is a condition that is easily missed by busy GPs. If your child presents with the symptoms, speak to your GP about your suspicions or visit a paediatrician who specialises in muscles and joints. You could also try speaking to your child's PE teacher who may have more information on this physical condition.

The **Hypermobility Syndromes Association** will also be able to help.

Diagnosis

If a child has possible HSD, they will be referred to a specialist who will examine them to get a holistic idea of the child's daily life, their activities, symptoms and how severely they are affected. Examinations may involve pushing and pulling muscles, blood tests, x-rays, gross motor movements like walking or running and assessment of joint movement.

HSDs are diagnosed through a combination of the child's symptoms and their scale on something called the Beighton Hypermobility Score. This is a 9-point system that scores patients according to the movements of their joints including elbows, knees, fingers and trunk.

Treatment

There is no cure for HDS, hEDS or EDS, but the conditions can be managed through exercise, physiotherapy and pain management. Surgery is not recommended but may be required to repair sporting injuries sustained through hypermobility.

What can I do to support my child?

- **Encourage exercise** - strengthening the muscles around hypermobile joints is the best way to protect them from injury. This can be difficult because it is usually exercise that brings on joint pain, but encouraging your child to keep up their sports and exercises prescribed by a physiotherapist is very important to managing their symptoms in the long run.

- **Shoes that fit** - a visit to a podiatrist and making sure your child has supportive, well fitting shoes and insoles if required can help ease leg, hip and ankle pain, as well as reduce the risk of injury.

- **Physiotherapy** - these medical practitioners are best placed to create tailor-made exercises that will support your child to strengthen their muscles and avoid injury. A referral from your GP should enable your child to access this service through the NHS.

- **Sports specialists** - speak to the PE department at your child's school or their sports club for advice on training that may help develop targeted muscle groups.

- **Self-management** - encouraging your child to persevere with their exercise and work through discomfort is the best way to empower them to manage the condition on their own. This is especially true with milder cases.

- **Tiredness** - it can be confusing to understand the messages fatigue is telling you. On one hand, you may be tired because you have done too much and need a rest, or your body may be telling you it needs more exercise and an increased level of fitness. Your child may find it particularly difficult to understand which of these messages is being sent, so supporting them through this is important.

- **Occupational therapy** - this is a type of support that looks at your child's daily activities and works out how they may be improved. This will include items such as their desk chair or mattress. You may be able to request an OT assessment through school.

- **Weight management** - an important part of everybody's health, this can be especially true for children with HDS. Excess weight will put extra strain on already fragile muscles, joints and skin.